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ABSTRACT

Care-givers, as a group, generally fare physically and emotionally as well or better than the population at large, at least in the early stages of their elderly relative's convalescent period. Fifty-one care-givers discussed their physical and emotional symptoms just as their relative was being discharged from a health facility and two months later. From this time-limited study it was possible to isolate restricted mobility--the feeling of being "tied down" as a major problem experienced by care-givers across all socioeconomic groups. This indicates a need for respite services which would periodically relieve the demands on care-givers and allow them necessary time for themselves. (BF)

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STRESS IN INDIVIDUALS CARING FOR ILL ELDERLY RELATIVES

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STRESS IN INDIVIDUALS CARING FOR ILL ELDERLY RELATIVES

Benjamin G. Danis, Ph.D.

Throughout the United States today there is an increasing demand for alternatives to institutionalization for our elderly. Several recent studies have demonstrated the physical, psychological and economic benefits of maintaining the elderly in the community (H.E.W. Report, 1977: Kim, 1976). This evidence - plus the demands of the American public and policy makers at all levels of government - has resulted in a proliferation of programs designed to assist family and friends in caring for their elderly in the community.

The goal of these programs - to prevent or delay the institutionalization of the elderly - is praiseworthy. But, in our enthusiasm over community-based care, we have neglected to ask some essential questions. In designing services and methods of service delivery, planners often make the assumption that the family members of the elderly are a primary resource in the health care system. Yet, we have not stopped to question the validity of this assumption. Certainly all research reports that when parents can no longer manage for themselves, children both expect to and do offer help (Robinson, 1976; Shanas, 1968; Sussman, 1965; Townsend, 1952). But a family's willingness to care for an ill member says nothing about its actual ability to do so. Previous research has documented the disequilibrium which often occurs in families who provide care for a seriously ill member. All too frequently, the care-giving family members develop pathological physical and psychological symptoms of their own. What previous research has not examined is how well families are able to respond to the physical and psychological needs of their elderly relatives. The research which I conducted in Syracuse, New York

during 1977 considered two questions. What stress do families experience in caring for an elderly relative? Secondly, which factors affect that stress associated with care-giving?

Design

My research consisted of personal interviews with the relatives of patients who were 60 years or older and about to leave a hospital or extended care facility. These relatives were identified as the patients' primary care-givers by the social service staff of the respective health facilities. I first interviewed 51 care-givers just as their elderly relative was being discharged from a health facility. I reinterviewed these same care-givers two months later. At both points in time I collected data on the care-givers' actual physical symptoms (using the Cornell Medical Index), their anxiety symptoms (using the Spielberger Trait-State Anxiety Scale), and self-report measures of health status and perceived stress. For comparative purposes I collected the same four health and anxiety measures from a group of control subjects matched on age, sex, race, income, and marital status. This matching procedure allowed me to ask the question: Do individuals who care for convalescing older relatives experience and manifest more stress than individuals matched on significant characteristics but who are not currently caring for an older relative?

A second question which my research asked was: Which factors affect the magnitude of stress which care-givers experience over a two-month period? The factors which I hypothesized might affect the magnitude of stress included:

1) the severity of the patient's physical impairment;
2) the affective relationship between the care-giver and the patient;
3) a change in the care-giver's living arrangements;
4) the solitary or shared nature of care-giving;

5) the presence of a confidant in the life of the care-giver;

6) the financial strain which the care-giver experienced in caring for the patient;

7) the helpfulness of religion for the care-giver;

8) the income, education, and employment status of the care-giver;

9) the patient's morale; and

10) other recent events in the life of the care-giver.

These factors, which became the independent variables in my research design, had been shown to effect the health and anxiety of individuals in previous gerontological and stress research (Blenkner, 1965; Brody, 1966; Cath, 1972; Holmes and Rake, 1967; Maddox, 1976).

Analysis

To answer the question of whether care-givers experience more stress over a two-month period than matched controls, I ran matched paired t-tests between the two groups at Time 1 and again at Time 2. By subtracting the Time 2 score on each dependent variable from the Time 1 score for each subject, I was able to determine whether care-givers experienced a greater change in their stress levels throughout the two-month period than did controls.

To test the relative impact of the independent variables on the health and anxiety of the subjects, I ran multiple regression analyses on each of the four dependent variables at Time 1 and again at Time 2. Only those independent variables with a significant zero-order correlation to the dependent variables were included in the regression equation.

Results

In reporting the results of this research, I will first describe the demographic characteristics of the care-givers. Secondly, I will report the effect of the independent variables on the health and anxiety levels of the subjects. Finally, I will discuss the findings concerning the relative stress levels of care-givers and control subjects.

Description of Care-givers

The data support the notion that the responsibility of caring for older family members falls mainly to women. The majority of the experimental subjects in my sample were middle-aged, married, Caucasian women who reported middle-range family incomes. Daughters and daughters-in-law together constitute the largest subgroup of care-givers. The responsibilities of caring for an older relative are as likely to fall solely to the care-giver as they are to be shared with other family members. These findings reinforce the concerns of practitioners over the conflicted situation in which the middle-aged children of ailing parents often find themselves, caught between the needs of their spouse and children and the increasing needs of their parents and parents-in-law (Cath, 1972; Savitsky and Sharkey, 1972).

The responsibilities of care-giving varied among these individuals. For a few individuals, this role entailed no more than a daily telephone call and a weekly visit. For some few others, care-giving involved moving the patient into their home and completely rearranging their living space and daily schedules. For the majority of the care-givers, however, providing care involved frequent errands, transportation to doctors' appointments and daily telephone calls. Accordingly, when the subjects were asked how their lives had been affected by their relatives' illness, the most frequent response concerned their restricted mobility and time spent away from their own families.

The problem of restricted mobility surfaced among families of all economic levels and appeared to cause the greatest general difficulty. Because of the pervasive nature of this problem, it certainly deserves the attention of planners who wish to support families' efforts to care for their elderly in the community.

Factors Affecting Stress

Which factors actually affect the degree of stress which care-givers experience?

First, the independent variables of Confidant, Education, Employment Status, and Morale had little or no impact on the dependent measures of stress at either Time 1 or Time 2.

Secondly, it appears that certain independent variables - such as Religion and Recent Life Events - have an impact on either the physical or psychological state of a subject without affecting the other state in a significant manner.

Finally, the affect which independent variables had on the care-givers' stress levels varied considerably between Time 1 and Time 2.

A conclusion which I drew from these regression analyses is that speaking in global terms about a family's "stress" during a period of care-giving yields limited value. Any meaningful discussion of this stress should include mention of the specific point in time during the care-giving process, the specific elements within the process which cause the greatest difficulty and the idiosyncratic tendency of each individual under study to respond in a primarily somatic or psychic manner to stress. These considerations may seem obvious. Perhaps they are. It is all the more surprising, therefore, that so much past stress research is unidimensional in its outcome measures and its time frame.

Stress Levels

How do the actual stress levels of care-givers compare to those of matched controls?

At the time of patient discharge from a health facility (Time 1), care-givers register nearly equal anxiety as control subjects. Their ratings of their own health also show no difference from the controls' ratings. Care-givers perceive themselves to be under somewhat greater stress than the control group, but this difference is not significant. What does differ significantly between the two groups is the number of health symptoms which each group reports. Surprisingly, it is the control group which reports the greater magnitude of health symptoms.

Two months later (Time 2), experimental subjects and controls once again rate their health quite similarly and register nearly equal anxiety. Although not significant statistically, control subjects report greater perceived stress than experimentals at Time 2. The surprising findings of more health symptoms among the control subjects reoccurs at a statistically significant ($p \leq .05$) level.

This study was based upon the belief that caring for a convalescing older relative is a disruptive and stressful life event. The literature is replete with case studies which reinforce this belief. Yet, the study's findings indicate that the care-givers do not experience more stress pathology than control subjects on measures sensitive to stress response. And, in fact, the health of care-givers appears somewhat better than that of control subjects. How can the findings of this study be reconciled with findings of stress among care-givers of patients in other studies (Binger, 1969; Davis, 1963; Hadley, 1974)?

One explanation might be that the age and illness of the patients in my study differed from the age and severity of illnesses cited in previous research. Most research on care-givers has focused on the parents of seriously ill or dying children or on middle-aged spouses who have been widowed.

Neugarten (1968) has described how an event can be conceived as "on-time"

or "off-time" in one's life depending on whether one considers it among the events likely to occur during a given stage of life. In this way individuals form expectations of facing certain events at different times in their lives.

Relating this concept to the present and previous studies, few parents expect their young children to contract polio or die of leukemia. Similarly, most husbands do not expect their wives to die and leave them widowers in their fifties. These events are generally unexpected in the lives of family members surrounding a patient; therefore, they could be described as events which are "off-time".

In contrast, the event of caring for an older parent or spouse in ill health is often an expectation for at least one member of a family in middle age. From observing parents caring for grandparents, friends caring for their own parents or their spouses, the expectation of caring for an older family member is culturally shared and perpetuated. Consequently, this event can be described as "on-time" in the lives of most middle-aged and older adults. This difference between the "timely" nature of the care-giving in the present study and that same behavior in previous studies could account for the disparate stress reactions among the care-givers in the various studies.

An alternate explanation for the study's surprising findings could be found in the work of Groen (1964). This Dutch physician reports a similar finding of better health among persons undergoing an objectively stressful experience in his study of Jewish citizens of the Netherlands interred in Polish concentration camps during the Second World War. From health records which Groen kept on his Jewish patients prior to and following their captivity, he notes a decrease in frequency, and even cure, of peptic ulcer, asthma, ulcerative colitis, migraine, and hyperthyroidism during their confinement. Groen acknowledges the cruel and threatening nature of life in concentration camps but reports that, emotionally, life for the prisoners took on a peculiar simplicity. The annoyances and frustrations of life

prior to the war were replaced by the singular and emotionally consuming task of survival. Conant's (1977) study of prison populations reports similar findings. Prisoners register significantly lower blood pressure readings than non-prison control subjects matched on age, sex, and race.

A possible interpretation of the current study's findings is analagous to Groen's conclusion. During the two-month period of care-giving under study, those individuals who function as care-givers may not react as sensitively to certain daily tensions and conflicts due to a new primary focus - namely, the needs of their convalescing relative.

Conclusion

In conclusion, this study indicates that care-givers - at least at the beginning of their elderly relative's convalescent period - fare physically and emotionally as well or better as a group than the population at large. Unanswered are the questions: How long does this superior level of health last among care-givers? At what point in the care-giving process are the demands likely to affect their health and spirits in a negative fashion? Only a study which examines the care-giving process over time can begin to answer these questions.

From the present time-limited study, it has been possible to isolate restricted mobility - the feeling of being "tied down" - as a major problem experienced by care-givers across all socioeconomic groups. I would hope that this finding could be used in urging planners and policy makers to consider the need for respite services which would periodically relieve the demands on care-givers and allow them necessary time for themselves, their husbands, wives, and children. Families want to care for their elderly relatives outside of institutions. It is incumbent upon us to provide them with the supports necessary to do so.

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